DOCUMENT RESUME

ED 293 259 EC 202 458

AUTHOR	Binkard, Betty; And Others
TITLE	Brothers & Sisters Talk with PACER.
INSTITUTION	PACER Center, Inc., Minneapolis, MN.
PUB DATE	Sep 87
NOTE	37p.
AVAILABLE FROM	PACER Center, Inc., 4826 Chicago Avenue South, Minneapolis, MN 55417 (free).
PUB TYPE	Viewpoints (120)
EDRS PRICE	MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS	Adjustment (to Environment); Adolescents; Autism; Behavior Disorders; Cerebral Palsy; *Childhood Attitudes; Congenital Impairments; *Coping; Deafness; Developmental Continuity; *Disabilities; Downs Syndrome; Elementary Secondary Education; *Family Relationship; Individual Development; Learning Disabilities; Mental Retardation; *Peer Relationship; *Siblings
IDENTIFIERS	*Long Term Care

ABSTRACT

This booklet presents excerpts from interviews with siblings (ages 10-28) of persons with a range of handicaps, including Down Syndrome, cerebral palsy, learning disabilities, deafness, autism, seizure disorder, genetic disorders, and mental retardation. It is arranged in order from the youngest person interviewed and continues through successively older siblings. This is intended to help the reader watch the maturing process from the somewhat limited understanding of the first interviewee, through the adolescent years when normal sibling strife can be exacerbated by the presence of a handicap, to the young adult years when siblings have built lives outside the family home and look back upon their childhood relationships with a more removed perspective. The comments of the siblings vary widely, but among the topics covered are relationships with parents, school-related experiences, reactions of their friends to their siblings' problems, level of understanding they had as a child about the handicaps involved, the responsibilities they bore for the care of their sibling while growing up, and their concerns about future plans and longterm care for their sibling. A list of resources is included. (VW)

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BROTHERS & SISTERS TALK WITH PACER

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Many, many special thanks to the brothers and sisters whose willingness to share their experiences, emotions, and thoughts made this booklet possible. Through their openness, they've given us insight into a group of people who've often been without a public voice.

Introduction

Over the last several months, PACER has conducted interviews with several siblings of brothers and sisters with handicaps. The following accounts are based on the interviews.

Providing a voice for siblings and their experiences was thought important for several reasons:

Siblings are instrumental figures in any family. In families with a handicapped member, siblings have additional importance since - as adults - they may have a very involved responsibility for their brother or sister for many decades to come.

Even within the families, the sibling experience has an extra dimension. In contrast to parents of handicapped children, for whom the unique experience begins only when they themselves are already adults and the child is born or diagnosed, for siblings the experience usually shapes their childhood. It's a life-long relationship.

Yet siblings have remained almost voiceless. Little is written about their thoughts or understandings. They often lack an opportunity to help make decisions about their brother or sister who's handicapped - yet the outcome of the decisions may have a great impact on their own lives in the future, depending on the degree to which they are responsible for their handicapped sibling.

This booklet is an effort to provide a voice for these key persons.

The number of siblings interviewed was certainly not large enough to yield specific conclusions about the

sibling experience of everyone. Indeed, the accounts are as varied as the individuals themselves.

Still, readers will note that several common themes emerge.

It's possible that readers will find themselves bothered by some of the comments that may seem unfair or indicative of an immature perception. During the interviews, PACER made no attempt to impose an adult sense of judgment onto what the young people see as happening in their lives and families. Rather, it was thought that to be of most help to parents, it was important for the young people to voice what they are feeling, not what they expect an adult to want them to feel. It's interesting to note that the oldest person interviewed remarked that some of the things she thought that her parents expected of her when she was a youngster were a product of her own imagination and a distortion of anything her parents had actually communicated to her.

When compiling the interviews into this booklet, PACER decided to begin with the youngest person interviewed and continue through successively older siblings. It's interesting to watch the maturing process from the somewhat limited understanding of the first interviewee...through the adolescent years when normal sibling strife can be exacerbated by the presence of a handicap...to the young adult years when siblings have built lives outside the family home and look back upon their childhood relationships with a more removed perspective.

Sarah

Sarah is ten years old. Her older brother, Sean, who is 13, has Down syndrome. He's different, she says, because "he can't learn as fast as other people."

"Kids tease him, and don't want to play with him because he's like that," she regrets.

"I just tell them to let him play, too," she explains. "Like he can play baseball in the summertime. I tell the other kids, 'He's no different than anybody else - he was just born with a different problem.'

"Sometimes I wish he were different," she says and then responds with a puzzled look when asked why. "Because," she explains patiently but as though the answer must be obvious, "I think he'd have more friends if he weren't 'that way'."

They go to different schools and take different buses so spend little time together away from home, she explains. Her thoughts of her brother are mostly of playing baseball and soccer together with their dad in the back yard.

Her friends don't laugh at Sean, she emphasizes, adding that "I've told them he has.....I'm sorry, I can't remember the right name for it....well, anyway, I say that he can't learn as well as we can."

Her mother, however, has been puzzled by Sarah's relationships with her friends. She rarely invites anyone to their home, and her mother had thought she was perhaps an introvert by nature. During a school conference, however, her classroom teacher told her mother, no, that at school the girl was one of the more popular children and usually surrounded by friends.

Sarah hasn't really thought about what life will be like for Sean in the future. Right now, her main concern is about his getting lost - twice he's wandered away from home and couldn't be found for several hours.

He's a good brother, though, she feels. "A lot of times, he'll try to help me with things," she points out positively.

"It's kind of funny," she adds. "If Mom lets us stay home together by ourselves, he always says he's going to babysit me. I don't say anything, but really I'm watching him."

Beth

"If you had a chance to talk with parents who have both handicapped and nonhandicapped children, what would you tell them about the sibling experience?" Beth, a 16-year-old quiet and thoughtful girl, was asked.

"I think," she responds after a pause, "I'd want them to understand that sometimes siblings are going to get jealous of the extra help and attention that a brother or sister who's handicapped receives. Parents shouldn't get mad about the jealousy or make the kids without a handicap feel too guilty about it if sometimes they resent the extra attention. Parents have to sit down and talk to the brothers and sisters who aren't handicapped about what the handicap really means. Kids don't automatically understand it by themselves.

"Maybe the other kids need some help, too, understanding that the handicap won't go away, that it will be there and it's a fact of life."

Beth's older brother, Allen, has cerebral palsy and an emotional and social disorder that appears to be related to self image.

"I love my brother," Beth continues, "but I'd like to understand more about his handicap. I don't really know why he acts the way he does.

"I wonder about him a lot. He doesn't have friends. People shy away from him. My parents and I would like him to be normal and have friends. We see him hurting and we hurt, too. I have a lot of guilt about Allen. I wonder why the other kids and I can't accept him for what he is.

"Sometimes, he's embarrassing though. He likes to brag about things that aren't true to try to gain acceptance. I can see kids laughing at him because of his bragging.

I'm not sure if I'm embarrassed because of his physical handicap or because he acts the way he does.

"My mom and dad say we have to understand the way he acts. But I wonder if his behavior is really part of his handicap or if it's just his way of refocusing attention away from the way he looks onto something he sees that maybe could be good about himself.

"I guess I'm not sure that all of his behavior is something we have to accept. Maybe we're not doing him a favor by allowing it.

"I think handicapped kids can have a lot of problems because they're always being put down and they may need help to build up a good image of themselves that's real," she speculates.

"I'd like to join a group for siblings if there were one. I guess I'd even be willing to try to start one if I knew other brothers or sisters who would like to join," she says. "Sometimes you feel like you're the only one who's gone through this. I haven't ever been able to share most of my feelings."

"Allen is a good brother in a lot of ways. He's a really caring person and he'll always stick up for me. He'll take me to a movie when I don't have any money, and I know if I were in trouble, he'd always be right there to rescue me.

"But I don't know how to help him," she explains. "I'd like to hear what other people have done. He comes home and yells at Mom and me. He wants so much to be normal, and there's all the anger.

"I try to help him, but he won't let me. I want to talk with him - let him get his anger out in the open - maybe I can help him understand what's gone wrong between himself and other kids. I don't think he understands how much I do care about him. But it's

hard. He blames his handicap for all his problems, and he's so angry at home.

"I have a lot of fear inside for Allen. I think I have a good future ahead - I work very hard in school and do well - but what will happen to him? I'm sure he'll stay at home with my mom and dad a lot longer than I will, but will he ever be able to get married and have kids?

"I think he and I will be close someday, though. The foundation is solid. I just want to find a way to help him. I am going to start learning more about the kinds of programs he might need when he's an adult.

"But right now, it's so frustrating. It's hard to find a way to let him know you love him. He might not show it, but you know he needs your love. I want to understand more about what's inside him. I'd like to talk to other siblings and see how they feel."

Bill

Thinking about his younger brother Gene's genetic disorder, albinism, and what it may mean for his own future as a parent has led Bill, who's 16, to a sophisticated definition of *handicap*.

"I guess my sister and I both could have kids who have albinism, but they could be normal, too. I don't think it would matter that much. There's not much you could do anyway," he says thoughtfully.

"I don't really consider my brother's albinism a handicap, except for his vision impairment. That does affect how he functions. He wears dark sunglasses outside and has to put on strong suntan lotion during sunlight hours. He's considered legally blind. and I think he has difficulty seeing things far away. But it's still something he can compensate for.

"I'd think of a handicap as something that's extremely difficult to compensate for, something that keeps a person apart from everyone else and interferes with what they want to do.

"My brother does look kind of different, but that doesn't really affect *him* -- if that's a handicap for other people, well, problems with somebody's appearance, that's **their** handicap," he distinguishes.

A teacher had told Bill that it might be interesting for him to go for genetic counseling. Bill says, "It might be fun to find out. I'd go out of curiosity, but I don't think it would change my mind."

Bill knows that Gene gets teased on the bus sometimes, but adds, "The people who know him don't tease him. The kids who are my age and my sister's are more curious than wanting to ridicule.

"Gene says at home, though, that sometimes teachers don't always understand. They try to help but can end up doing things that hinder him. He never wants special treatment."

That his brother has albinism doesn't usually bother him, Bill says, except, "Sometimes you're standing in a crowd and you hear someone talking and you think, 'Why can't they keep it to themselves.'

"Being a brother, sometimes I've had a chance to stop some of the misgivings about albinism. I'll explain what it is to other people and educate them. I remember our junior high life sciences textbook said people with albinism can never go outside. It was nice to be there to correct that misconception.

"I think Gene's having albinism has made me more accepting of people and look differently at them. If you are exposed to something, you do change. I tend to look harder and deeper at my friends, at the kind of people they are in handling themselves and treating other people."

Mary

"I guess I have more resentment now about the attention my brother gets than when we were younger," says Mary, 17, whose younger brother Andrew has a learning disability. "When we were younger, he seemed like a little kid and it was OK for him to get a lot of help. Now it seems like my mom will sit for hours with him while I'm just expected to do my own homework for myself."

Asked to explain what she understands about his learning disability, Mary says, "I know about his medication and that he can't learn as quickly as other kids. But it's hard for me to understand why he needs so much extra help. Now that he's a freshman, I can't understand why he can't pick up after himself. I've always had to. I do think he could take on a little more responsibility.

"Nonhandicapped kids can get pushed aside when their brothers or sisters have handicaps," she believes. "Andrew seems to get help naturally - it's like attention to his needs is 'built into the system.' I'm the bad one, but he can do no wrong. He makes all the messes, but I get into trouble if I don't empty the dishwasher."

She realized early, she recalls, that Andrew had some special problem. "I never actually said, 'Oh, he must be handicapped.' But I started to notice as time went on that I could do things faster. I remember that we'd have races like who could get into their pajamas first, and I always won. I started to wonder why after awhile."

"I feel bad for him," she continues. "Sometimes it seems weird that it's my brother who's this way. He's my brother, but he's not like me.

"I don't feel embarrassed about him though. With his kind of handicap, well, he does strange stuff. But it's

like the stuff everybody's little brothers do. It's sort of what you expect from little brothers."

In the future, she says, "I see Andrew living at home a lot longer than I will. But I think he'll do just fine - it will just take him longer. Myself, well, I want to do something and make a lot of money. Andrew, I see doing something where he's helping people.

"Right now, I think it would be helpful if I understood more and could appreciate more about what he goes through and why my folks have such different expectations of me than they do for him. If there were a group for siblings, I guess I'd like to talk with them about the issue of parents and their different expectations."

Sue

The last few years have been ones of special pain for her family, says Sue, 17, but also ones that have brought new shared support between herself and her parents.

The years have been a time when John, her younger brother who is 14 and deaf, moved out of his childhood, when he had many school and neighborhood friends, into adolescence, when old friends became more conscious of popularity and not wanting to be different in any way from everyone else and started to abandon the boy who "talks so funny."

John, who was one and a half when the family learned he was deaf, had begun in a special school program right away. He signs, but can also speak, so the family doesn't use signing at home. He shifted from a neighborhood school in sixth grade to a special program in a school in another district - primarily because of the teasing he was experiencing, Sue says.

Next year, however, he wants to return to the high school near their home, the one she and their older brother have attended. It will mean being back among the same kids who used to tease him so badly.

"A lot of people make fun of him, and it hurts me so much, too. He *knows* he's different, but he really hasn't *felt* he is. It's so hard to hear him ask Mom why a kid will act mean to him.

"He's really very secure with a lot of inner strength. It probably came from my mom who's always told him to stick up for himself. John doesn't want us to see him cry. Gary, my older brother, and I tend to be protective, but John thinks we make too big a deal of stuff. He wants to handle problems with the kids himself.

"One time I got so angry at some kids, I went out and asked them how they'd feel if they were John. They said they weren't deaf so they didn't have to worry. I didn't accomplish much, but telling them how I felt helped me.

"A good friend and I have talked over how worried I am about what will happen to John in high school next year. My friend said he and my other good friends will help me talk to the other kids - maybe if the freshmen know that my friends and I are ready to pounce, it will be a deterrent," Sue hopes.

Her hurt for her brother is especially painful because she thinks he's such a special person. "Maybe because he's deaf, he's a nicer person," she theorizes. "He seems so much nicer than my friend's little brothers. He's had to learn social skills to be accepted.

"I think I'm probably nicer myself to all handicapped kids because I know what they go through. I don't judge people by how they look and appear on the outside.

"In my friends, I look for understanding of what I go through and of John. Otherwise, I can't express myself. I wait until I really know people and see what kind of a person they are inside before I judge whether I can be close to them or not," Sue explains.

"But I feel bad when John sees me going off with my friends and wonders why he doesn't have many. He'll be at home when I'm out having fun, and it makes my mom feel bad. I feel guilty and I don't know how to handle it.

"But he doesn't want to talk about the social problems of being deaf and he doesn't want us to be hurt on his behalf. When he was going through the real bad period before he went to the special program in another school, one night I heard Mom crying. I knew exactly

how she felt, and we talked for a long time," she remembers.

"My mom and dad had told us right away when they realized something was wrong with John's hearing. They helped us to understand that there was nothing that could be done to make his deafness go away and that we would need to help him and be especially kind.

"They explained right away what they would need to do to help John. I think it's really important to include other kids in the family right away. One of my friends didn't know for a long time what was wrong with her sister, and it was really confusing for her. If kids are in on it from the beginning, they can start adjusting along with their parents and learn how to live with it. Even if you don't know exactly what's wrong for awhile, it's still better that everyone understand there may be something wrong than to go through a long period of seeing that one kid is different but never talking about why.

"I've gone to school with John once in awhile, and it's really helped me understand what his struggles are," Sue explains. "I can see how much he's learned and how well he copes. He doesn't pity himself, and he doesn't mope. I have a lot of respect for him.

"As a kid, I saw the COUNT ME IN show (PACER's handicap awareness program for schoolchildren that uses puppets to convey information and understanding about children with handicaps), and it seemed to help the other kids and their attitudes. John loved to see the show when it came to his school - he'd be proud then that he was deaf because no one else could be an example."

Sue believes that her parents have also helped her brothers and herself by always setting aside times to be alone with each of them. "They've always taken Gary and John and me out individually at different times so each kid got a chance to be with them by ourselves.

"I'd tell parents, too, to share their sadness with the other kids. Like the time when Mom and I just sat and cried together. I could be supportive to her. Somebody outside our family wouldn't have known so well what she was feeling."

Cassie and Andrea

"All my life I've seen people stare at my sister," relates Cassie, 18, "and now I realize how glad I am not to be like one of those people."

Cassie and Andrea, who's 19, have an older sister Jennifer who has cerebral palsy and is mentally retarded. A younger sister and an older brother, who now lives in California, makes theirs a large family, which both describe as extremely close and, as Cassie says, "secure within ourselves."

"My earliest memories of Jennifer," Cassie recalls, "are when we still lived in our old house so it must have been before I was two. I didn't think of her as handicapped - she was just another one of my sisters - but I always knew there was something different. She'd always call us by funny names.

"As time moved on, I pretended I wasn't embarrassed by Jennifer. But I really was when my friends were around. By the time I was 14 or 15 though, I realized my good friends loved her, too. I hadn't realized that before. I hadn't given her a chance.

"I felt then that I had to stop being worried about how new friends might react. There were two boys whom I'd met at school and thought were my friends. The first time they met Jennifer though, they laughed. I told them to leave our house.

"I'd grown up helping to take care of her. My brother and sisters and I had never had full responsibility for Jennifer foisted on us, but the responsibility just seemed natural, like your name. Everyone felt it.

"I've completely picked up my parents' attitudes and love for Jennifer. We've all grown to understand that she has special needs. None of us has ever thought she

was being treated better because we always thought that's the way she should be treated.

"Jennifer wasn't going to have all the positive things the rest of us would. I was never jealous. I couldn't be. I have so much, can do so many things and have all the friends I do.

"My parents treated us equally - but to be equal Jennifer had to have more direct attention from our parents. We never felt shut out because of her needs though. Our whole family always got attention.

"I can't imagine my life without her," Cassie emphasizes. Right now, she explains, Jennifer is finishing high school and lives with a woman who entered the family's life 14 years ago as a summer helper and is now married with children of her own. It's a phase in Jennifer's movement to adult life and a world of her own.

"She'll always be involved with our family on weekends and on trips," Cassie says, "but she has a life of her own, too, during the week. I know that everyone she's grown up with will continue to be involved in her life though.

"Being involved in her life has made me a better person, I think," Cassie feels. "I can understand something about what people with mental retardation are feeling.

"For one thing, I know they all have their own personalities. They're not all just one big blob who 'works the same'.

"Jennifer has probably achieved more than I have. She's been through so much. She couldn't even talk when she started school; now she can, and she can understand others. She's really fulfilling her potential. I'm not sure the rest of us are.

"First you have to really know someone like my sister to really understand and appreciate her achievements."

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Talking about her life with a handicapped sibling, Andrea, the sister who comes between Jennifer and Cassie in age, thinks about some ironies.

Her parents, she emphasizes, never expected or required the children to act in a certain way.

"They wanted us to express our feelings," she remembers. "They'd say 'If you're uncomfortable when Jennifer's around your friends, don't feel guilty. Those feelings are very normal.'

"They've always told us that Jennifer's problems are theirs to worry about and that Jennifer's future is for them to deal with. I know that they've made plans so that her future can be happy and secure - and have left us free to get on with our own lives."

Yet, as Andrea talks about her family, it's clear that Jennifer has always been a happy and essential part, with siblings who have voluntarily pitched in to be with her, often canceling their own social plans when Mom and Dad needed some help.

In fact, she and Jennifer shared a bedroom for 14 years, Andrea says. Although her parents had told her again and again that she could have a room of her own, she thought Jennifer would feel deserted if she left their room. Not until Jennifer finally indicated that she was the one who wanted to have a room of her own did Andrea make the move.

She and her sisters and brother have always had full lives of their own, Andrea says, but doing things together as a family with Jennifer involved has been an equally rich part.

And despite the freedom granted the brother and sisters by their parents to pursue their own futures, all of their future plans involve close continuing ties to Jennifer's life.

Like Cassie, Andrew expresses her sense that she's a wiser and better person because of having grown up with Jennifer.

"I have a different outlook on life than many other people my age. I understand that you can't take anything for granted. And you have to be able to look at the positives, where the balance falls. With Jennifer, there are negatives, but there's so much more that's good.

"I'm very involved now with activities for persons with mental retardation. Sometimes I get upset at some of the nonhandicapped people who work with me and seem to be involved as some kind of an ego trip...like, 'Look at me and what a nice person I am for helping out these poor helpless people.' I feel like I understand so much more about persons with handicaps and how they feel trying to overcome so many frustrations. We're proud of what Jennifer can do.

"My sisters and I can turn into three really big monsters in public if someone makes fun of her when we're around. But we don't want pity for her. She deserves respect as a person."

Rachael

"I really don't know what we'd have done if the tests had shown I could pass on OI (osteogenesis imperfecta)" says Rachel, 21, when asked about the genetic counseling she and her fiancee had sought before their recent marriage.

"I've always loved kids and assumed I'd have some someday. I hadn't really thought about what my mother's and sister's OI could mean for myself. But my husband did bring it up when we were engaged and thought it was something we should explore. Luckily, we found out there was no way I could pass it on."

Rachael had grown up as the only nonhandicapped person in her family. Her father has a physical disability and her mother and younger sister have OI, often called the "brittle bone" disorder, which can be inherited. Persons with OI experience frequent bone fractures, often from the usual activities of daily living.

Because her parents and sister couldn't participate as fully in household duties, much of the responsibility for their home fell on Rachael. "I didn't resent their dependency, though," she says. "It's been my whole life. I always had to bring Sandy to the bathroom and help her get ready before I could go to school."

She did mind the "guilt trip" she feels she was sometimes exposed to though. "If I wanted to do something, Sandy had to go, too. If I protested, my dad would say, 'You should just be thankful you're not handicapped,'" she recalls. "I think my sister got favored a lot, psychologically as well as physically. It was always my fault whatever went wrong."

As she grew older, Rachael felt perhaps her family was relying on her too much. After high school, for the first time she spent several weeks away from home at a

camp and describes it as an "effective weaning period." Her family made other arrangements for help and successfully adjusted to the time when Rachael would leave her childhood home for good.

She and her husband continue to live nearby and return to her parental home often - but now with visitor status.

Her husband, she says, had told her later that he'd been a little uncomfortable the first time he met her family, having never closely known anyone with a handicap.

"I never knew he'd felt that way until we talked about it much later," she remembers. "Now, he's much more patient about things than I am. If we haven't visited my folks for awhile, he'll be the one to remind me to call and ask when we can come over."

Rachael has become very proud of her sister. "Sandy's a lot of fun. She's overcome a lot by her cute personality.

"We had a lot of discussions while we were growing up, and I did have a chance to help 'shape' her. I'd always encourage her to be self sufficient and help her see how she could do things."

Sandy has worked at a couple of jobs during high school, Rachael explains, and loves work related to animal care. "I've encouraged her to go to college and that's her plan now. She wants to train as a veterinarian's assistant. Moving away from home to go to school in another city will be a big change for her, but she seems to have everything lined up that she'll need, and I really think she's going to succeed."

Paul

"At times, when we were younger, I really hated our family situation. I used to wish my sister was anywhere but here and I'd think, sometimes, that maybe she should be put in an institution. Now that I'm older and have learned more about institutions, I don't think that anymore," says Paul, a 21-year-old college student whose older sister, Stacy, has autism.

Autism is a hard-to-understand disorder that is now thought to be a neurological impairment. It affects the way sensory input is handled by an individual and causes serious social and emotional problems. Person with autism can seem to be in worlds of their own. They may have serious problems with communication, might show unusual responses to sound, touch, and smell, and frequently engage in self-stimulation activities.

Stacy's autism has meant a lot of screaming, crying like a baby, and emotional unpredictability.

"Trying to explain it to other people is extremely difficult," according to Paul. "People know what something like mental retardation is. Or if a person has a physical handicap and their mind is OK, other people can relate to them and understand what the handicap is.

"But with autism," Paul continues, "well, I'm not sure to this day that I really understand it. My folks were wonderful in trying to help me understand what was wrong with Stacy. But understanding it, even as much as I do, doesn't make it easier to live with. She'll start screaming so loudly the whole neighborhood can hear. But she's never ashamed. She has no social awareness.

"I try to give her some guidance sometimes on how to act. But she really resents someone telling her what to do.

"Do I love her? It's hard. Sometimes I do when she acts nice for awhile. But it's difficult to love someone when they don't do anything pleasant," he reflects.

Since he was born "into it," he explains, he grew up knowing there had to be allowances made. He recalls first sensing that something was wrong with the way his sister behaved when he visited friends' homes and noticed that their brothers and sisters acted very differently from his.

In addition to appreciation to his parents for doing their best to help him understand, he credits their having made opportunities for him to do things without his sister's presence. Family friends would take him along on outings, he remembers, and his dad would make sure he and Paul had time alone.

But family outings in public were rare. Stacy was too volatile and unpredictable to allow many good times together. The family has a lake cabin, but their times there have been private, avoiding possible explosions in public.

"I've felt much sorrow," Paul says, "both for Stacy and myself. I'd never want children of my own to experience what I have or what Stacy goes through.

"Someday, if I do marry and have children, I really hope that no one person will have needs that have to be so much more important than everyone else's."

He thinks his own parents, given a very difficult problem in the family, handled it as well as possible. He'd advise other parents of children with handicaps to follow their example of recognizing that their other children will have needs of their own and compensating for the extra time spent with the handicapped child by doing things with the other children when Mom and Dad can be alone with them.

"Parents should try to find ways not to let the child who's handicapped dominate all of the family's worlds," he urges.

As Paul finishes his college years, he's thinking more and more about leaving their family home, but finds it difficult to imagine his mother coping with their home and sister by herself. His father died a couple of years ago, and the loss of a good and kind man whom the family loved deeply is still keenly felt.

His mother, Paul says, has continually stressed that he and an older brother should not feel a sense of burden about Stacy. They've researched group homes and intend that she will be able to live away from the family home. Paul also knows that his mother has done estate planning to help ensure Stacy's future.

Still, he can't imagine not being there to help. "I'm very bothered by what I've seen happen to my mother. She has a master's degree but has never been able to use her eduation in her own field because of my sister's needs," he worries.

"I want to move out and have a home of my own. I'd like to be able to have some parties at my place - I've never been able to have them here. I've always had to go to other people's parties.

"But it's really difficult to think about moving out. I'm glad I like the Twin Cities area because even when I leave this home, I'll never want to be farther than a phone call away."

Mark

"I suppose my earliest memories of Tom are of us playing around the neighborhood and he was always willing to take any dare, no matter how far fetched. He was in trouble a lot with everybody's parents because of his temper and the accidents he'd cause. He was always trying to impress people and would do anything to be the center of attention," Mark, 24, recalls.

His brother Tom, who's a year younger, has a seizure disorder and serious learning disabilities. As a young adult, he's also had surgery for a brain tumor that doctors believe had existed without detection for many years.

"People probably didn't know what Tom's medical problems were when we were little kids," Mark speculates. "They just thought he was a *weird* kid, the one you could count on to do something foolish."

Mark himself found his brother kind of an embarrassment but never felt Tom's strange behavior and poor reputation were any reflection on himself, he says. He'd try to give Tom some advice about how to act but felt his hands were tied as any suggestions were rejected. It wasn't until years later, Mark says, that he associated some of the weird things his brother did with his learning disorder.

He can't recall exactly when he became aware of what his brother's medical problems were. "I think my understanding of his disorders came in a step-by-step fashion. As actual situations occurred, my mom would talk about how there were some things Tom couldn't help or control. She always told me about the things going on in his life that were significant.

"I learned to accept differences in our personalities and in the amount of self control we each had and that I

shouldn't fly off the handle when he'd done something I didn't like. There were differences in discipline between my mom and dad, though. Sometimes my father would punish Tom for something my mother had said he couldn't control. It was confusing. Sometimes I'd feel like it was about time he got punished. Other times I'd think the punishment was wrong and had to go in my room and shut the door," he recounts.

Prior to junior high, Mark says he had realized Tom had a seizure disorder, and the neighborhood kids became used to it. "Most of the kids were quite helpful," he remembers. "Another kid had two sisters with handicaps so the neighborhood kids weren't freaked out by someone having a disability.

"When I made a new friend, their initial reaction was always, 'Wow! What's happening?' That wore off as soon as I'd explained. I think that when kids made fun of Tom it was more because of his inappropriate behavior than because of his seizures," Mark remembers.

"I guess it was in junior high that I started to be aware of some of the long term implications of Tom's disorders and be sad for him. He was falling behind in school and no longer just one grade behind me. Until then I hadn't had a sense that Tom's situation worried or bothered him. But when I got to junior high and was having such a good time myself, I realized that the whole experience wasn't going to be the same for Tom as for me. I was sad, but I didn't know what I could do."

Love and affection for each other was difficult for both brothers to express, Mark explains. "Tom could never express his emotions with me except for anger. His other emotions such as love were felt only by our mom. Often, I'd gain a sense that Tom really did like me only when Mom would interpret to me what he was

feeling and tell me about comments he'd made when I wasn't around.

"Sometimes, expressing love and happiness for him did come easily, though. One time when Tom was in fifth grade, he was the catcher for our T-ball team, and we were in a championship game and one run ahead in the bottom half of the last inning. The tying run was on third, and the guy was at least 20 pounds heavier than Tom. Anyway, the batter hit a ground ball, which I caught and threw to Tom. He got creamed by the runner from third but stayed in front of the plate and held onto the ball and got the guy out. Everyone in our family became very emotional."

As they've grown older, Mark says that they're able to have a better older brother/younger brother relationship. "Before I used to feel uncomfortable giving him advice or talking about what I'd learned about something like dating when Tom hadn't had a chance to have any experience in that respect yet. Now that he's able to lead a more independent life and have more social experiences of his own, it's easier to talk together."

Currently, Mark has been living away from home in another city for several years as he finishes his education and begins a career as an attorney. Tom lives in a semi-independent apartment with some supervision and has a supported employment job.

"There's still some envy and bitterness on Tom's part when I come home and we're together again," Mark says. "Especially when he sees me going out to be with my friends, he can get mad and resentful.

"The other night he blew up because I wanted to watch a TV program before taking him back to his apartment. Probably for the first time, I sensed it would be OK to get upset back at him. I vocalized how I felt when he was so angry at me, the unfairness of his accusations and how much I did love him and was hurt by his

explosion. He became very subdued and reflective, and I think a good thing had happened."

Mark feels that Tom will always need someone from the family to live in the vicinity to watch what's happening with his life, help to coordinate the programs he's on, and be there for guidance when problems come up that Tom can't handle by himself.

"I know my mom will handle it as long as she can," Mark feels, "but someday it will be my job. It's something I want to do. Part of the reason I've chosen law as my career is to enable myself to deal with some of the problems that Tom will always face.

"I'm not sure I want to stay in the Twin Cities, but I think it would be too drastic a move for Tom to uproot him and move him elsewhere, especially now that he's finally on the way to establishing some kind of life for himself here. I'd like to go away for awhile and get myself established, and then eventually I'll probably need to move back. My family and I haven't talked about it directly, but this is what I see for the future."

Marsha

Marsha is 28 and now an advocate, both for her sister Kim, who is three years older and retarded, and, as part of her job, for abuse victims.

Becoming an adult helped ease much of the stress between herself and Kim, she says. "I do love her now," Marsha emphasizes, "but it took a long time."

When she was very young, Kim had seemed like what an older sister should be, Marsha recalls. Kim's problems with seizures, and retardation that appeared to occur following a series of seizures that caused her to be hospitalized, had not surfaced immediately.

"At first," Marsha says, "Kim could handle things. She was the leader. I became angry when she no longer was continuing in that role. I wanted to have an older sister who could tell me what to do.

"To me, as a child, her seizures were terrible. It was awful to watch and listen to her when one happened. She could have a seizure any time, any where, and I found it very embarrassing.

"She caused problems for me at school, too. I'd get into fights because of her, so I held her responsible for most of my problems.

"Also, she has a one-track mind and can't reason too well. She goes off on tangents a lot. I wanted her to be quiet, to just shut up. It's to her credit she ignored me. Fortunately, she has never been intimidated by those of us who tried to shut her up, and today it means she can advocate for herself and go out into the world and express herself.

"But then, I blamed her for a lot of things. I probably knew she didn't have control over certain things, but she still really irritated me," Marsha remembers.

"Today I can understand I misunderstood my role at that time. I thought then I was supposed to beat up on kids who were mean to her. I think that was just my perception though. I don't really think now that my parents had put as much responsibility on me for Kim as I thought they had at the time.

"It's important to remember, too, that our childhoods took place two decades ago. At that time, our family was really on its own. It was like we were at the mercy of whatever agency had anything at all to offer, and we weren't very sophisticated.

"Our family was so involved in struggles to get some help for her that we didn't talk much about what was happening and what it all meant.

"I think today families have more opportunities - and they should take advantage of them - to sit down together and explain what's happening.

"I can see now that there can be some similarities to what happens to an alcoholic's family: i.e., any dysfunctional person can have a lot of power. Kim didn't wield power so much as she held passive power. Her situation controlled so much of what went on in our family.

"For instance, her medications could go awry and she'd have a seizure just before an event we'd planned, so the event would have to be postponed or canceled.

"One person's disability can change almost everything about a family," she believes. "I think families have to talk about it and acknowledge what's occurring.

"Also, I think parents will have to create communication opportunities between themselves and their children. Parents will probably have to ask some leading questions, too, because kids won't initiate telling their folks about some of the bad things they feel. Their feelings can include a lot of guilt and

shame - not the kind of things that children feel very proud of themselves for feeling. But I think it's important that the emotions be brought out into the open and discussed.

"For one thing, whether or not their parents or others have told them this, nonhandicapped kids think they're expected to feel lucky because they're not handicapped. But they also may think, 'O.K., I know I'm lucky, but I'm still angry or hurt or ashamed or whatever.' There are a lot of messy feelings involved so parents will probably need to draw out their kids. Maybe they won't even get a response at first, but the door should be opened.

"Also, I thinks it's a good idea to network with parents of other nonhandicapped kids as well as with parents of kids who are handicapped. It helps to keep expectations accurate.

"Expectations can get distorted if parents think about their other kids only in relation to the one who's handicapped. For instance, they might expect the nonhandicapped kids to be too perfect. Or, if the handicapped kid came first, then the parents might think that everything the later kids do is a miracle.

"I'd also tell other parents not to despair if their other kids experience some bad feelings. I had it all - guilt, shame, distorted anger - and I worked it out. Becoming an adult did help.

"Today, not because of guilt but because I genuinely want to, I am helping my mom monitor and coordinate Kim's programs. She's living in a semi-supervised apartment and has financial and medical aid programs in place. But she is a vulnerable adult.

"I think that things go better for people like Kim when service providers know there is a family member on the scene and paying attention. I've started going to meetings now. It occurred to me once when both Mom

and Dad were out of town that I had no idea where Kim's financial aid came from, who the reponsible people and agencies were in her life, and who were the key caring figures I could turn to. So I started learning.

"Sharing some of the responsibilities with my mom has made me see her in a different light. After the first meeting I attended, I thought, 'How has Mom ever been able to do this all of Kim's life?' It's so intimidating. There are always more of 'them' than of us. Kim is really involved in a maze, and someone besides my mom and dad needs to know about it all."

Resources for Siblings

1. Parents and siblings may both be interested in the Sibling Information Network. Through its newsletter, the network puts siblings in touch with each other and carries news of special interest to all the family members of a person with a disability.

Published quarterly, the newsletter costs $5.00 yearly for an individual subscription and $15.00 for an organization's subscription.

To subscribe, contact:

The Sibling Information Network
Connecticut's University Affiliated Program
School of Education, Box U-64
249 Glenbrook Road
Storrs, Connecticut 06268.

2. Articles and other publications about siblings:

a. Chinitz, S.P. (1981). *A Sibling Group for Brothers and Sisters of Handicapped Children.* Children Today, 10(6), 23-33.

b. Exceptional Parent, (1982). *Jerry Got Lost in the Shuffle: Problem as a Sibling.* 12(4), 45-51.

c. Featherstone, H. (1980) A Difference in the Family: Living with a Disabled Child. New York: Basic Books.

d. Lobato, D. (1983). *Siblings of Handicapped Children: A Review.* Journal of Autism and Developmental Disorders, 13(4), 347-364.

e. Moses, K. (1982). *Brothers and Sisters of Special Children: A Dialogue with Kenneth*

Moses. Interactions, 1(2), 12-18.

f. Powell, T.H., and Ogle, P.A. (1985). Brothers and Sisters - A Special Part of Exceptional Families. Baltimore, Maryland: Paul H. Brookes.

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3. Persons with access to a university or college library may be interested in research about families and siblings by **Patricia F. Vadasy**, Rebecca R. Fewell, and Donald J. Meyer, and Greg Schell.

4. The National Sibling Network is an organization for brothers, sisters, and adult sons and daughters of persons with mental illness. The Network offers workshops and group sessions. A newsletter, *The Sibling Bond*, is available for $7.50 a year. For more information or to subscribe, contact Julie Johnson at 612-872-1565 or by mail at:

The National Sibling Network
P.O. Box 300040
Minneapolis, MN 55405.